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Coalition for the Advancement of Medical Research
supporting funding of stem cell research

TESTIMONY FOR KRIS GULDEN
On Behalf of the
COALITION FOR THE ADVANCEMENT OF MEDICAL RESEARCH
Before the
SENATE COMMERCE COMMITTEE SCIENCE SUBCOMMITTEE
January 29, 2003

Good afternoon Senator Brownback and Members of the Committee. Thank you for the opportunity to testify today on the value of somatic cell nuclear transfer (SCNT), commonly referred to as therapeutic cloning. My name is Kris Gulden, and I am here on behalf of the Coalition for the Advancement of Medical Research.* The Coalition is comprised of more than 75 patient organizations, universities, scientific societies, foundations, and other entities advocating for the advancement of breakthrough research and technologies in regenerative medicine in order to cure disease and alleviate suffering. Today, I consider myself the voice of hope for the millions of Americans who may benefit from therapeutic cloning.

Along with the Coalition for the Advancement of Medical Research, the National Academies of Science, 41 Nobel laureates, and the vast majority of the American public, I support a ban on human reproductive cloning. However, it is imperative that we protect important areas of medical research that offer hope to so many of our citizens. As a person living with paralysis caused by a spinal cord injury, I know how urgently a cure is needed. I do not expect a cure tomorrow, or even next year, but we may have before us our greatest chance to cure diseases like ALS, Alzheimer's, Parkinson's, cancer, diabetes, and even paralysis resulting from spinal cord injury. I do not intend to overstate the promise of the research, but you can't overstate the hope that it offers people like me.

Everything about my life changed on May 26, 1998, when I began a bicycle ride that I never completed. I started my ride as a 31 year-old triathlete. I was employed as a police officer in Alexandria, Virginia. I'd been on my bike for an hour when I was struck from behind by a motor vehicle. In addition to a traumatic brain injury, four broken vertebrae, two broken ribs, a broken breastbone and clavicle, I bruised and displaced my spinal cord at the T4 level. As a result of that accident, I have been forced to surrender my career as a public servant, robbed of the hobbies that sustained me, and left unable to perform some of the daily, personal freedoms that able-bodied people take for granted. It should not be difficult to understand why I feel so passionately about furthering research into nuclear transplantation – a technique that has been called the most promising advance in the history of medicine.

Within a few months of my injury, I began to follow research that was being conducted at the Miami Project to Cure Paralysis. At about the same time, I was experiencing tremendous healing and discovered that I could move my legs. I rapidly progressed to walking with the rolling walker. However, a rare complication of a spinal cord injury – a

disease called syringomyelia, has caused me to lose considerable function. I have not, though, lost hope.

I ride a stationary bike that uses electrical stimulation to power my legs three days a week, for an hour at a time. I take therapeutic horseback riding lessons, use a Nordic track – like device for standing and additional aerobic exercise, and I spend a month each year doing biofeedback in Miami. The biofeedback shows that my brain is sending signals out to my leg muscles. My spinal cord is still healing. My commitment to getting out of this wheelchair is unwavering. I am doing my part – even five years post-injury, to maximize my potential for return of function. But I can't do it alone. I need medical researchers to continue exploring new technologies that could forever rid me of my wheelchair.

Five years ago, I was excited when I learned about the restorative potential of Schwann cells that were being studied in Miami. When stem cells were isolated – especially embryonic stem cells, I became even more convinced that there would be a medical breakthrough to help me reclaim the life I left behind. Now we're talking about nuclear transplantation - a technique to create embryonic stem cells that could be used to treat a myriad of diseases and disabilities. With each additional discovery, my hopes soar. In the five years since my injury, I've come to accept that scientists are making progress, and that the question of a cure is no longer a matter of "if", but "when".

I understand that the word "cloning" causes many people to imagine the worst possible abuses. But there is a critical difference between cloning to produce a baby – reproductive cloning – and therapeutic cloning techniques to create stem cells. While I am not a scientist, I am aware of the process of therapeutic cloning. It is unconscionable to me that the United States Congress would choose to prohibit research that could lead to cures and treatments for many devastating diseases and disabilities.

I recognize that none of these areas of research – adult stem cells, embryonic stem cells, and nuclear transplantation – comes with a guarantee, but they should all continue. I also understand that the limited potential of adult stem cells makes working with embryonic stem cells preferable. One may argue that there are already existing lines of embryonic stem cells available for research. But that number is dwindling. The creation of embryonic stem cells through nuclear transplantation seems to me a reasonable step in the quest to free people from the inescapable medical conditions with which they live.

For me, the only escape from paralysis is to dream. In my dreams, I still walk. I run, I play basketball, and I wear the uniform of the Alexandria Police Department. When the sun rises each morning, it brings reality with it. I rise to the sight of a wheelchair, yet I rise with the hope that maybe this will be the morning I can move my legs.

Please don't take away the hope of countless Americans who could benefit from therapeutic cloning and the family members and friends who love them and care for them. On behalf of the Coalition for the Advancement of Medical Research I again thank the Committee for its deliberations and for the opportunity to speak to this issue.

* The Coalition is comprised of nationally-recognized patient organizations, universities, scientific societies, foundations, and individuals with life-threatening illnesses and disorders, advocating for the advancement of breakthrough research and technologies in regenerative medicine – including stem cell research and somatic cell nuclear transfer – in order to cure disease and alleviate suffering.